Outcomes in neurodevelopmental and genetic disorders

Edited by two leading authorities and written by a team of international experts in the field, this book describes the causes, course and treatment of a variety of developmental and genetic disorders, including attention deficit disorder, fragile X syndrome and autism. There is a particular focus on the course of disorders over time and prognosis in adulthood. Outcome is an area often overlooked in other books dealing with developmental disorders, but is an issue of great importance to parents and carers, and one that has important implications for education, health, social and employment services.

As well as offering succinct and up-to-date summaries of the most recent research, the authors provide clinicians with practical guidelines for intervention and management with children and young adults. This book is essential reading for clinicians and psychologists, and anyone working with or caring for individuals with neurodevelopmental disorders.

Patricia Howlin is Professor of Psychology at St George's Hospital Medical School in London. She is Editor of *Autism: International Journal of Research and Practice* and Annotations Editor of the *Journal of Child Psychology and Psychiatry*. Her book *Autism Preparing for Adulthood* won the NASEN Special Educational Needs prize.

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Preface

Much of the research and the majority of descriptive and clinical accounts related to developmental or early onset genetic disorders have an understandable focus on children. The parents of young children with such conditions have a pressing need to know why the disorder has occurred, whether it can be prevented, what are the genetic implications for other family members, what the long-term outcome is likely to be and perhaps most importantly what they can do to help their child. As time moves on, teachers and others responsible for educational provision need to know what problems these children are likely to face in gaining access to the regular school curriculum and what extra help will be needed in order to meet any special educational needs. And, at every stage, paediatricians, child psychologists and psychiatrists, health visitors, language therapists and many other professionals are likely to be called on for support and advice. It is clearly crucial therefore that those involved in the care, education or therapy of children with developmental and genetic disorders are fully apprised of the nature of the problems with which they have to deal, and of how they can help to minimize difficulties, enhance skills and prevent the development of secondary problems.

However, conditions such as Rett syndrome, fragile X or autism do not suddenly disappear around the age of 16 to 18 years. Neither do problems related to language, specific learning difficulties or attentional deficits cease at these ages. Unfortunately, all too often, the help and care that children and their families have received comes to an abrupt halt when these children reach adulthood. Teachers are no longer available to provide advice on education or other issues, and specialist clinical services are typically replaced by generic adult services for people with chronic physical or mental health problems, or intellectual impairments. Faced with an ever increasing clinical load, few practitioners working in these areas can be expected to spend much time also learning about children's disorders. And anyway, how relevant is such knowledge likely to be? Knowing about the early development of a young girl with

Rett syndrome, for example, is unlikely to be of great help when it comes to dealing with the physical and emotional problems sometimes experienced by older women with this condition. Similarly, the early *specific* problems of a child with language or reading difficulties may be replaced by a range of different social or emotional problems in adulthood.

Knowledge about the long-term outcome of childhood disorders is crucial if families and clinical and social services are to be able to plan adequately for adulthood. Thus, our aim in the present volume has been to examine some relatively well-known conditions with an onset in childhood but from a developmental perspective. What happens to these children as they grow up? Does the condition change with time, bringing new difficulties or a decline in severity? What problems are parents, carers and the individuals themselves likely to face, and how can these be effectively managed? Above all, what can be done to help individuals live lives that are as full and as satisfactory as possible?

As well as addressing such issues in the various chapters, we have sought to provide up-to-date and accessible summaries of what is currently known about the causes of these conditions (particularly those related to genetic factors) and the principal problems with which they are associated. And, because research into adult interventions remains limited, we highlight therapies and approaches that seem to be helpful for children, in the hope that knowledge about effective strategies may be adapted to work with adults.

The conditions themselves vary in severity, pervasiveness and prevalence. Some, such as attention deficit disorders, specific reading and other learning disorders, and language impairments are relatively common. These are conditions that most professionals working in adult education, medical, mental health or learning disability services are likely to encounter. Thus, knowledge of the adult sequelae of childhood difficulties, and the ways in which they may change over time, is particularly important.

Other disorders, including tuberous sclerosis, Rett syndrome, Prader-Willi, Angelman, Williams and Smith-Magenis syndromes and various metabolic disorders are relatively rare. However, their severity is such that it is crucial for those working in adult services to have at least some basic knowledge about what physical, behavioural, social and emotional problems may be manifest in adulthood. Even more important is access to information on how to manage these difficulties when they do occur.

Finally, there is a group of disorders that occur relatively frequently, but in which the presentation can be very variable. Fragile X and Down syndrome for example, are amongst the most common known chromosomal causes of

intellectual disability, but levels of functioning can range from borderline/average to profound mental retardation. Cerebral palsy – which is the single largest cause of severe physical handicaps in childhood – and autism are both spectrum disorders. Both can lead to profound and pervasive handicaps, or relatively mild impairments that with appropriate support can be greatly helped. However, this means that outcome can be significantly affected – for better or worse – by the degree of support that is available, not only in childhood but also in later adolescence and early adulthood. Even in the case of those whose disability is less severe, appropriate provision can make the difference between leading a rich and fulfilled life, or one that is dogged by continuing social problems and emotional turmoil.

It is our hope that by providing an accessible and up-to-date account of what happens to children with developmental disorders as they progress to adulthood – and what help they may need to see them safely along that path – the journey both for them, and those caring for them may be made a little easier.

Patricia Howlin and Orlee Udwin